A PARENT'S GUIDE TO

Congenital Adrenal Hyperplasia (CAH)

12/2007

Congratulations on the birth of your new baby! As part of the routine newborn screen, Utah tests all babies for Congenital Adrenal Hyperplasia, or CAH. In the initial newborn screening test, your baby tested outside the normal range for CAH, however more testing will be needed to determine whether or not your baby has CAH.

What is Congenital Adrenal Hyperplasia (CAH)?

CAH is a group of autosomal recessive genetic conditions, meaning it must be inherited by the baby from both parents. Each parent of a baby with CAH carries one normal gene, and one CAH gene. When a baby inherits two CAH genes, one from each parent, the baby will have a disorder. CAH is characterized by an inability to adequately produce the hormones cortisol and aldosterone. The deficiency of these hormones may be life threatening, so it is important to contact your baby's medical home provider, doctor or clinic as soon as possible.

What to do right now:

Your baby's doctor will arrange for the CAH testing, and give you necessary instructions. This testing needs to be done immediately, even if your baby looks healthy.

If your baby has any or all of the following it could mean an emergency. Please seek medical attention immediately.

- Difficulty eating/refusing breast or bottle
- Vomiting
- Sweating or cool, clammy skin
- Rapid breathing
- Pale skin color
- Dry mouth
- Fewer than one wet diaper in eight hours or little wetness (urine) in diapers
- Excessively sleepy, hard to wake up
- Sunken fontanel (soft spot on head) when held upright

What happens next?

The results from the testing will be available 3-5 days from when it was received in the lab. Your baby's doctor or someone from the Newborn Screening Program will call you when these results are available.

If you have any questions or concerns, you may call the Newborn Screening Program (801-584-8256) or your baby's medical home provider, doctor or clinic.

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Newborn Screening Program